

# Discovering the path to Unlimited Breath

| 9:00-9:30   | Registrations  |                             |  |
|-------------|--|-----------------------------|--|
| 9:30        | Introduction-opening President of Hellenic Cystic Fibrosis Association, Anna Spinou                                    |                             |  |
| 9:30-11:00  | Welcome talks  |                             |  |
| 09:30-09:34 | Greek Minister of Health, Adonis Georgiadis *  |                             |  |
| 09:34-09:39 | General Secretary of Health Services of Greek Ministry of Health, Lilian Venetia Vildridi                              |                             |  |
| 09:39-09:43 | President of Hellenic Medicines Organization (EOF), Evangelos Manolopoulos   |                             |  |
| 09:43-09:48 | President of Pharmaceuticals of National Organization for Healthca<br>Karpodini  | re Provision (EOPYY),Theano |  |
| 09:48-09:52 | Head of Pharmaceuticals of National Organization for Healthcare Provision (EOPYY), Chara Kani                          |                             |  |
| 09:52-09:55 | CEO Eurordis-Rare Diseases Europe, Virginie Bros Facer   |                             |  |
| 09:55-10:00 | CEO CF Europe, Hilde de Keyser   |                             |  |
| 10:00-10:06 | Representative of European Cystic Fibrosis Society Patient Registry-ECFSPR, Lutz Nährlich                              |                             |  |
| 10:06-10:10 | Vice President of the Patient Association of Greece, Memi Tsekoura   |                             |  |
| 10:10-10:15 | President of the Onassis Foundation, Antonis Papadimitriou   |                             |  |
| 10:15-10:19 | President of the Greek National Transplant Organization, Georgios Papatheodoridis                                      |                             |  |
| 10:19-10:24 | President of the Onassis Cardiac Surgery Center, Ioannis Boletis   |                             |  |
| 10:24-10:28 | President of the Greek Institute of Child Health, Christina Kanaka-Gantenbein  |                             |  |
| 10:28-10:33 | Head of Cystic Fibrosis of Medical Genetics Laboratory, National and Kapodistrian University of<br>Athens, Maria Tzeti |                             |  |
| 10:33-10:37 | Data Protection Officer of Greek Ministry of Health, Dimitris Zografopoulos  |                             |  |
| 10:37-10:42 | Head of the Department of Therapeutic Protocols and Registries of Greek Ministry of Health, Panagiota Mitrou           |                             |  |
| 10:42-10:46 | Hospital at Home Scientific Officer of Greek Ministry of Health, Ioannis Tsanakas                                      |                             |  |
| 10:46-10:51 | Representative of the Hellenic Pulmonary Society, Charalambos Moschos  |                             |  |
| 10:51-10:55 | President of the Hellenic Society of Obstetrics and Gynecology, Alexandros Rodolakis                                   |                             |  |
| 10:55-10:59 | President of the Hellenic Association of Pulmonologists, Stamatoula Tsikrika   |                             |  |
| 11:00-12:30 | Part A: Cystic Fibrosis in Children<br>Moderators: Anna Spinou, Konstantina Giannaki                                   |                             |  |
| 11:00-11:10 | The new face of Cystic Fibrosis: hopes and challenges  | Elpis Hatziagorou           |  |
| II:I0-II:20 | Modern management & holistic care for children with CF   | Argyri Petrocheilou         |  |
| 11:20-11:30 | New approaches in managing gastrointestinal complications in CF patients   | Maria Fotoulaki             |  |
| 11:30-11:40 | Transition of adolescents with Cystic Fibrosis from pediatric to adult care: new insights                              | Manolis Paraskakis          |  |
| 11:40-11:50 | Nutritional interventions for patients with pancreatic insufficiency   | Xristina Katsagoni          |  |
| 11:50-12:00 | Latest advances in nutrition for children with Cystic Fibrosis   | Anastasia Gkampeta          |  |
| 12:00-12:30 | Q & A  |                             |  |



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| 12:30-13:00                | Lunch break   |  |
|----------------------------|---|--|
| 13:00-14:30                | Part B: Cystic Fibrosis in Adults & Lung Transplants  Moderators: Spinou Anna, Giannaki Konstantina   |  |
| 13:00-13:10                | New challenges in Cystic Fibrosis   | Filia Diamantea  |
| 13:10-13:20                | Triple combination elexacaftor/tezacaftor/ivacaftor in CF patients without $\Delta F508$  | Katerina Manika  |
| 13:20-13:30                | The experience of managing adult patients with Cystic Fibrosis  | Georgios Pitsidianakis   |
| 13:30-13:40                | Lung transplants: Where we stand in 2024  | Iraklis Tsagkaris  |
| 13:40-13:50                | Cardiac surgery management for patients preparing for lung transplant   | Themistoklis Hamogeorgakis   |
| 13:50-14:00                | Recovery and care after lung transplant surgery   | Fotis Theodoropoulos   |
| 14:00-14:05                | Second chance at life: The experience of lung transplantation through the eyes of a patient   | Agorasti Voulgaridou   |
| 14:05-14:30                | Q & A   |  |
| 14:30-15:00                | Coffee break  |  |
| 15:00-16:00                | Part C: Hellenic Cystic Fibrosis Association 4l Years of Transforming life with CF Moderators: Anna Spinou, Konstantina Giannaki  |  |
|                            |   |  |
| 15:00-15:10                |   |  |
| 15:00-15:10<br>15:10-15:20 | Moderators: Anna Spinou, Konstantina G  | iannaki  |
|                            | Moderators: Anna Spinou, Konstantina G  HCFA 1983-2024: Opening the path to "Unlimited Breath"  Online group cognitive behavioral psychotherapy program of  | iannaki<br>Anna Spinou   |
| 15:10-15:20                | Moderators: Anna Spinou, Konstantina G  HCFA 1983-2024: Opening the path to "Unlimited Breath"  Online group cognitive behavioral psychotherapy program of HCFA  CF Helpline "Unlimited Breath": A support phone line for everyone  Living with Cystic Fibrosis: Stories of strength from patients and caregivers | iannaki Anna Spinou Stavroula Rakitzi Eleni Atsave   |
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\*TBC











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#### **Speakers**

Adonis Georgiadis, Greek Minister of Health \*

Lilian Venetia Vildiridi, General Secretary for Health Services of Greek Ministry of Health

**Evangelos Manolopoulos,** President of Hellenic Medicines Organization (EOF), Professor of Pharmacology, Medical School, Democritus University of Thrace

**Theano Karpodini,** President of Pharmaceuticals of National Organization for Healthcare Provision (EO-PYY)

**Chara Kani,** Pharmacist, Head of the Pharmaceuticals, National Organization for Healthcare Provision (EO-PYY)

Virginie Bros Facer, CEO of Eurordis - Rare Diseases Europe

Hilde de Keyser, CEO of Cystic Fibrosis Europe

**Lutz Nährlich**, Professor, Managing Senior Physician, General Pediatrics, Pediatric Allergology, Pediatric Pulmonology and Cystic Fibrosis, University Hospital Giessen and Marburg, Executive Committee Member of the European Cystic Fibrosis Society Patient Registry (ECFSPR)

Memi Tsekoura, Vice President of the GPatient Association of Greece

Antonis Papadimitriou, President of Onassis Foundation

**Georgios Papatheodoridis,** President of Greek Transplant Organization, Professor of Medicine, National and Kapodistrian University of Athens, Director of University Gastroenterology Clinic and Director of the Liver Transplant Unit, "LAIKO" General Hospital

**Ioannis Boletis,** President of Onassis Cardiac Surgery Center, Professor of Pathology - Nephrology, School of Medicine, National and Kapodistrian University of Athens

Christina Kanaka-Gantenbein, President, Institute of Child Health, Professor of Pediatrics - Pediatric Endocrinology, Director of the 1st Pediatric Clinic and Choremio Research Laboratory, National and Kapodistrian University of Athens, Endo-ERN Aghia Sophia Children's Hospital representative, Member of the National Committee for Rare Diseases, Scientific Officer of the Center of Expertise for Rare Endocrine Diseases in Children

Maria Tzeti, PhD, Professor of Genetics, Medical Genetics Laboratory, School of Medicine, National and Kapodistrian University of Athens, "Aghia Sophia" Children's Hospital

Dimitris Zografopoulos, Data Protection Officer (DPO) of Greek Ministry of Health

**Panagiota Mitrou,** Head of the Department of Therapeutic Protocols and Registries of Greek Ministry of Health

**Ioannis Tsanakas,** Emeritus Professor of Pediatrics - Pediatric Pulmonology, Aristotle University of Thessaloniki, Coordinator of the National Cystic Fibrosis Registry Working Group, Scientific Officer of Greek Ministry of Health Hospital at Home Working Group

**Charalambos Moschos,** Member of the Board of Directors of Hellenic Pulmonary Society, Pulmonologist, Attending Physician, Antituberculosis Department - Drug-Resistant Tuberculosis Unit, "Sotiria" General Hospital for Chest Diseases



### Discovering the path to Unlimited Breath

- **Alexandros Rodolakis,** President of Hellenic Society of Obstetrics and Gynecology, Professor of Obstetrics and Gynecology, National and Kapodistrian University of Athens
- **Stamatoula Tsikrika,** President of the Hellenic Association of Pulmonologists (EPNEL), Pulmonologist, Emergency Department, Athens General Hospital for Thoracic Diseases "Sotiria"
- **Elpida Chatziagorou,** Professor of Pediatrics Pediatric Pulmonology, Aristotle University of Thessaloniki, Head of Cystic Fibrosis Unit, "Ippokrateio" General Hospital, Thessaloniki
- **Argyri Petrocheilou,** Pediatrician Pediatric Pulmonologist, Cystic Fibrosis Department, "Aghia Sophia" Children's Hospital, Athens
- Maria Fotoulaki, Professor of Pediatric Gastroenterology, Aristotle University of Thessaloniki, Director of Pediatric Gastroenterology, Hepatology, and Nutrition, "G. Papageorgiou" General Hospital, Thessaloniki
- Manolis Paraskakis, President, Hellenic Pediatric Pulmonology Society, Associate Professor of Pediatrics, University of Crete, Head of the Pediatric Cystic Fibrosis Clinic, University General Hospital of Heraklion, Crete
- Christina Katsagoni, MSc, PhD, Clinical Dietitian-Nutritionist, "Agia Sofia" Children's General Hospital, Scientific Collaborator at Harokopio University
- **Anastasia Gampeta,** MD, PhD, MSc, Pediatrician, Lecturer in Medicine, Aristotle University of Thessaloniki, MSc Applied Nutrition and Health Promotion
- **Filia Diamantea,** Pulmonologist, Director, National Health System, Scientific Officer, Adult Cystic Fibrosis Unit, Sismanoglio General Hospital
- **Katerina Manika,** Associate Professor of Pulmonology, Aristotle University of Thessaloniki, Adult Cystic Fibrosis Center, Pulmonary Clinic, Aristotle University of Thessaloniki, "G. Papanikolaou" General Hospital, Thessaloniki
- **Georgios Pitsidianakis,** Director Pulmonologist, Head of the Adult Cystic Fibrosis Clinic, University General Hospital of Heraklion, Crete
- **Iraklis Tsagkaris,** Professor of Pulmonology Intensive Care Medicine, National and Kapodistrian University of Athens, Director of the 2nd Intensive Care Unit, Attikon Hospital, Scientific Officer of the Lung Transplant Center, Onassis Cardiac Surgery Center
- **Themistoklis Chamogeorgakis,** Director of the 2nd Cardiac Surgery Department, Head Cardiac Surgeon, Heart-Lung Transplant & Mechanical Support Unit, Onassis Cardiac Surgery Center
- Fotis Theodoropoulos, Attending Pulmonologist, Onassis Cardiac Surgery Center
- **Anna Spinou,** President of Hellenic Cystic Fibrosis Association, BOD Member of EURORDIS- Rare Diseases Europe, Member of Working Group of Greek Cystic Fibrosis Patient Registry, European Patients' Academy (EUPATI) fellow
- Konstantina Giannaki, Vice President of Hellenic Cystic Fibrosis Association
- **Stavroula Rakitzi,** Dr., Dipl:-Psychologist, Clinical Psychologist and cognitive behavioral Psychotherapist, Head of the Group Psychotherapy Program of Hellenic Cystic Fibrosis Association
- **Eleni Atsave,** Psychologist, MSc in Health Education and Promotion of Medical School, Head of the "Unlimited Breath" Helpline Program of Hellenic Cystic Fibrosis Association
- **Eleni Saltouridou,** Social Worker, Head of the "Unlimited Breath" Helpline Program of Hellenic Cystic Fibrosis Association